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## End of Life Doulas Bridge a Gap for the Dying

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It might surprise you to hear that a person with life-limiting or terminal illness spends only about 5% of their time with nurses, doctors, specialists, and the full range of hospice services. According to end of life expert [Dr. Allan Kellehear](#), this means that as much as 95% of their time is spent alone, with family and friends, and in the community — *not* engaged with medical professionals.

For most of us, dying is not a medical event. And ninety-five percent of the time is *a lot* of time to be alone. This is especially true when facing the last weeks and days of life. It is a lot of time that potentially goes unsupported and unwitnessed, even by loving, well-meaning family and friends. There are many barriers that prevent us from showing up for loved ones, even when it is needed most: we are more geographically diverse than ever, and there are often competing priorities in our day-to-day lives that must be balanced. Yet for those facing death, this time alone can breed feelings of isolation and loneliness, worry and despair about what's being done, what's not being done, and the uncertainty of what's next.

### Bridging the Gap

The truth is, on a good day, we need each other. We are social beings who thrive on connectedness – someone to talk to about things that truly matter, and the sharing of simple gestures of love and kindness that celebrate our preciousness and remind us we're not alone.

On a bad day, we need each other even more.

And on all of the days in between, contrary to the “independence culture” we live in, we need the presence of people who care deeply about us and our wellbeing. We need to be surrounded by those who can help us talk through crucial choices, help us reflect meaningfully on our lives, and reflect back for us the heart of who we are and the importance of what is happening in these critical moments of uncertainty.

This isn't weakness; this is essential to what it means to be human. We are hardwired for belonging and connection. We long to feel a sense of purpose that brings us meaning and fulfillment, particularly when we're confronting the reality of our own mortality. Our social structure doesn't always provide the heart-to-heart contact we need to sustain us in our need for making sense of life, processing the layers of loss that we are experiencing throughout the end of life process, and preparing for death.

Likewise, nothing quite kicks up our most fearful parts as much as when we are witnessing the affects of death and dying, or grief and loss, on others. While attempting to tend to our own intense emotions that arise, it can be difficult to be fully present to the needs of others. An end

of life doula provides emotional and practical support to help guide the dying and those who accompany them, through the dying process. In this role of companion on the journey, the end of life doula provides continuity of care and creates a valuable bridge to the services offered by the medical community.

### **The End of Life Doula Role**

There are people designated to help us into the world, so it only makes sense that there are people designated to walk with us as we leave it. In a nutshell, an end of life doula fills this non-medical, community-based role that meets the social-emotional, and psycho-spiritual needs of the dying and their circle of loved ones. Just as there are birth doulas to provide logistical and emotional support to expectant mothers as they prepare for birth, end of life doulas provide similar support to the dying as they transition into death.

End of life doulas invite engagement with the process of dying itself by providing opportunities for life review and legacy projects, planning for the last days and hours of life, for having hard conversations with loved ones, and for creating the space to talk openly and honestly about what the experience of dying is like for everyone involved. Demystifying and leaning into what is happening allows loved ones to show up more confidently, and allows the dying to then let go more easefully into the unknown of what's next.

In our largely death phobic culture, it is a relief and a necessity to have someone who is calm and comfortable be wholly present in the face of such uncertainty, especially for extended periods of time. End of life doulas provide a peaceful presence at the bedside, have the time to support the deep relationships families need, and have the expertise to address the complex needs and situations that occur at end of life.

### **A Beautiful Partnership**

There is a common misconception that the end of life doula role somehow takes the place of palliative or hospice care. However, this could not be further from the truth. As a community-based, non-medical role, end of life doulas serve as an important partner in the whole of a person's care team, working alongside the family to advocate for the desires of the person who is dying – before, during, and after death.

Further, they are able to work on behalf of both the care team and the family in supporting and making progress toward mutual goals. This becomes most important when we recall the 95% rule – there is big work that happens outside of the medical arena in helping a person and their loved ones prepare for death. An end of life doula serves as a trusted intermediary and partner on the journey.

### **Choosing an End of Life Doula**

Choosing an end of life doula requires research and discernment to find the right fit. And as with any profession, each end of life doula has a unique perspective on the work, different training and certification, as well as varying amounts and kinds of experience. Working with an end of life doula is often private pay; a bit like a life coach, but for dying. Rates will vary related to the experience and services provided.

It is important to ask questions, consider getting referrals, and get a feel for how they do their work. Do you resonate with what they say, and how they say it? Does it bring you a sense of comfort, trust, and relief? If so, move forward; if not, keep looking. Always trust your gut.

You know best.

## Staying Close to What Matters

None of us can know for certain what lies on the other side of death. Surrendering into the unknown — both for the person dying and for those closest to them — is one of the hardest things any of us will ever do.

And yet we all will do it.

What we do know is that death is a journey and a mystery and the road is often a difficult one. And, we do not need to travel this road alone. We have the support of the medical community, when needed. If we are fortunate, we have the support of family and friends, religious and social communities. Today, we are also fortunate to have the end of life doula who amplifies the opportunities for meaning, purpose, and healing available to benefit all those involved in care at the end of life.

As we become more familiar with their services, end of life doulas will be sought after to work around the clock, individually or in teams, bridging the gaps in support before, during, and after death. This deep companionship will further increase quality of life moments by assuring that the dying and their loved ones are able to invest their valuable energy and presence where it matters most.